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Pioneering Healthcare Law

Essays in honour of Margaret Brazier

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Chapter 10

Critical decisions for critically ill infants: Principles, processes, problems

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10 Critical decisions for critically ill infants

Principles, processes, problems

Giles Birchley and Richard Huxtable

Introduction

Deciding what is best for a critically ill infant can be fraught, particularly if the question before the parent, healthcare professional or judge is ‘to treat or not to treat?’. We explore the courts’ dealings with cases in which this ethico-legal question has been posed, inspired by Margaret Brazier’s work in this context with the Nuffield Council on Bioethics.¹ Specifically, we consider whether the clinical ethics committee (CEC) might improve the *principles* and *processes* by which resolution is achieved. The principle might appear straightforward: decisions must rest on the ‘best interests’ of the infant.² Yet this cardinal *legal* principle can have diverse *ethical* interpretations, such that the best interests of an infant are neither self-evident nor incontestable. When deciding, doctors should apparently engage in shared decision-making with parents, with the courts stepping in if agreement fails to materialise.³ Yet, how – or whether – consensus is achieved is also open to question, as is the role that the courts play when consensus cannot be found.

These questions of principle and process inevitably introduce ethical questions, whose answers apparently require ethical sensitivity. Are the courts equipped to bear the moral load?⁴ Perhaps CECs, increasingly available across the United Kingdom (UK), might have a role to play, since their functions include providing advice on ethically difficult situations.⁵ In assessing this service, we will not only advance normative arguments, but also make reference to the views of those closest to the dilemmas that can arise on the paediatric intensive care unit (PICU). The findings we report indicate variation in the perceived effectiveness of CECs, obstacles to non-health professionals’ access to CECs, and questions

1 Nuffield Council on Bioethics, *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*, (NCB 2006).

2 ‘Best interests’ can be considered synonymous with ‘welfare’: *Re B (a minor)(wardship: jurisdiction)* [1988] AC 199, 202 (Lord Hailsham LC).

3 *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33; *Glass v UK* [2004] 1 FCR 553.

4 J Montgomery, ‘Law and the Demoralisation of Medicine’ (2006) 26 LS 185.

5 UK Clinical Ethics Network <www.ukcen.net> (accessed 17 October 2014).

about the expertise and authority of committee members. Such insights suggest that work identifying and disseminating best practice is needed, if CECs are to deliver on their apparent promise.

The data we report comes from the *Judging Best Interests in Paediatric Intensive Care* (BIPIC) study. BIPIC is a qualitative empirical ethics study funded by a Wellcome Trust fellowship in Society and Ethics. After gaining approval from an NHS research ethics committee, the first author (advised by the second, amongst others) conducted in-depth, semi-structured interviews in three clinical centres (here named Hospital A, B and C). The study recruited 14 parents, 10 doctors, 8 nurses and 7 CEC members through senior clinical collaborators. Interviews focused upon the process of making decisions about very sick infants and were subsequently analysed using thematic analysis.⁶

Intractable disputes?

Two recent cases involving infants with severe neurological conditions illustrate the dilemmas that can be confronted on PICU. In both cases, the parents sought treatment, which the doctors judged not to be in the infant's best interests. In *An NHS Foundation Trust v R (Child)* (hereafter *Reyhan*),⁷ an infant, Reyhan, suffered from mitochondrial disease, which left him moribund and dependent on mechanical ventilation. His doctors sought to withdraw ventilation on the basis that continued treatment of his incurable and terminal disease would provide 'no benefit to him other than life itself'.⁸ His parents opposed this, motivated inter alia, by a religious belief in the sanctity of his life. During the hearing, the court heard a second medical opinion which confirmed the terminal prognosis yet favoured treating Reyhan because of the deleterious effect that non-treatment would have on his family.

Having taken nine months to reach the courts, the case was rapidly decided in favour of the hospital. At this conclusive point, Jackson J ordered a break in proceedings of two months before he made the final order, to allow Reyhan's family time to come to terms with the verdict. Reyhan's family launched fresh proceedings in the interim, aimed at overturning the prospective order, and Reyhan died whilst still actively being treated, five months after the hearing had begun.

The next year, in *An NHS Trust v AB* (hereafter *AB*),⁹ Theis J heard a similar case whose rapid passage through the courts contrasted sharply with that of

6 See further: G Birchley, 'Deciding Together? Best Interests and Shared Decision-Making in Paediatric Intensive Care' (2014) 22 Health Care Analysis 203; G Birchley, 'You Don't Need Proof When You've Got Instinct!: Gut Feelings and Some Limits to Parental Authority' in R Huxtable and R Meulen (eds), *The Voices and Rooms of European Bioethics* (Routledge 2015).

7 [2013] EWHC 2340 (Fam).

8 Ibid [20].

9 [2014] EWHC 1031 (Fam).

Reyhan. The infant, known as EF, had spent the sole year of his life in hospital with a degenerative neurological condition that manifested itself, among other serious symptoms, in worsening respiratory insufficiency. This had resulted in 11 episodes in which EF required mechanical ventilation, the most recent of which had led to court proceedings. EF's parents and doctors agreed that EF's decline was inexorable and that further aggressive measures should be withheld. However, EF's doctors felt that no treatment should be offered after ventilation was withdrawn, whereas EF's parents argued that withdrawal should be followed by a further 24-hour period in which supportive measures could be reinstituted. The parents' view was informed by the observation that such short-term support had proven efficacious in weaning EF from the ventilator in the past. On the basis that EF's doctors had no answer to this observation, Theis J decided on a compromise: EF was to be offered bag and mask resuscitation for 24 hours following withdrawal of his mechanical ventilation.

Problems of principle?

When seeking to resolve cases like *Reyhan* and *AB*, problems initially arise with regard to the principle(s) that purport to guide the resolution of parent–clinician conflict. Notwithstanding its familiarity and some statutory pointers,¹⁰ the ‘best interests’ standard is notoriously difficult to define; as Brazier puts it, this can be ‘an empty mantra’.¹¹ The principled basis of this standard is multi-faceted, which can make it unclear which values are actually influencing the resolution. We can understand best interests in (at least) three different ways: in *desire-fulfilment* theories, what individuals most desire conveys their best interests; in *hedonistic* theories, what makes individuals happiest is in their best interests; and in *objective-list* theories, best interests are independent of individual happiness or desire and align instead with objective accounts of the good.¹²

Of course, the theory that is chosen (whether overtly or otherwise) will affect the conclusions that are reached.¹³ Each of these theories feature in the law. Desire-fulfilment features, for example, in the Children Act's instruction that reference be made to ‘the ascertainable wishes and feelings of the child’ whenever decisions are to be made in their best interests.¹⁴ Hedonistic concerns surface when the courts favour the withholding or withdrawal of life-sustaining treatment in view of the infant's current or anticipated suffering, usually expressed in terms of his or her poor quality of life.¹⁵ The courts also insist that life has an objective value, such that there is a presumption in favour of upholding the sanctity of life.¹⁶

10 Children Act 1989, s 1; cf. Mental Capacity Act 2005, s 4.

11 M Brazier, ‘An Intractable Dispute: When Parents and Professionals Disagree’ (2005) 13 Med L Rev 412, 415.

12 D Parfit, *Reasons and Persons* (OUP 1987) 493–502.

13 D Degrazia, ‘Value Theory and the Best Interests Standard’ (1995) 9 *Bioethics* 50.

14 Children Act 1989, s 1(3)(a).

15 See for example *Re J* (n 3).

16 See for example *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181 [87].

Given its pluralistic inclination, the law inevitably encounters conflicts between the different values advanced in the name of best interests. We see this in *Reyhan*: the parents held ‘conscientious beliefs about the sanctity of life’,¹⁷ whilst his doctors cited quality-of-life considerations, arguing that continued ventilation ‘is delaying his death without significantly alleviating his suffering’.¹⁸ Deciding which (if either) of these accounts should take priority is not only practically challenging, but also philosophically fraught. Each of the three rival theories outlined has its difficulties,¹⁹ and there ‘is no clear calculus’ for determining best interests.²⁰ Identifying such a calculus will doubtless prove difficult, ‘given the plurality of ethical world views that can and do exist’.²¹

Yet, even if one can give the best interests standard some substance, there is another difficulty to overcome: determining whether the best interests of the infant should be considered of *paramount* importance (and thus overriding) or of *primary* importance (and thus coequal with other primary – principally family – interests).²² The Children Act favours the former approach,²³ but there is evidence of some inconsistency in the courts. In *Reyhan*, for example, Jackson J seemingly equivocates over whether the interests of those who are closest to the infant are relevant concerns for the court. He outwardly favours the paramountcy test, because he rejects the argument²⁴ that treatment should be continued in order to benefit the family.²⁵ Yet, he evidently considers parental interests to be a relevant consideration: despite having concluded that further treatment was against Reyhan’s interests, he allows the parents time to come to terms with the verdict. The judge’s reasoning thus indicates that the infant’s interests were a primary, but not overriding, consideration for the court.

On some occasions (albeit controversially) judges have been particularly explicit in their regard for the parents’ interests.²⁶ Whilst we can only speculate as to the exact situation in English law (at least, as it is applied), Seema Shah’s survey of 101 judgments in the United States is revealing, since she found that courts were evenly divided between those which saw the child’s interests as paramount and those which saw them as a primary consideration.²⁷

17 *Reyhan* (n 7) [14].

18 *Ibid* [12].

19 DeGrazia (n 13).

20 P Baines, ‘Death and Best Interests: A Response to the Legal Challenge’ (2010) 5 *Clinical Ethics* 195, 197; cf. J Herring, ‘Farewell Welfare?’ (2005) 27 *J Soc Wel & Fam L* 159, 160.

21 R Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or not to Treat?* (Routledge 2012) 85.

22 S Parker, ‘The Best Interests of the Child: Principles and Problems’ (1994) 8 *IJLPF* 26.

23 Children Act 1989, s 1(1).

24 *Reyhan* (n 7) [34].

25 *Ibid* [60].

26 See for example *Re T (a minor) (wardship: medical treatment)* [1997] 1 All ER 906; see also *NHS Trust v A and others* [2007] EWHC 1696.

27 S Shah, ‘Does Research with Children Violate the Best Interests Standard? An Empirical and Conceptual Analysis’ (2013) 8 *Northwestern Journal of Law and Social Policy* 121.

The obverse of the apparent inconsistency of best interests is that it is a flexible standard.²⁸ Whether this flexibility is wielded (in)appropriately will turn not only on which principles we think should be determinative, but also on *who* does the wielding. Since every other actor will operate in the shadow of the courts, it is to judges we should look most closely. In the absence of a prescribed hierarchy of values, judges, whether knowingly or not, will probably favour one or other of the different theories outlined earlier. In short, we are likely to confront incommensurable accounts of a critically ill infant's best interests, and be left with a problem of indeterminacy.²⁹ The judges will also dictate the processes that must be followed. So what are these processes?

Problems of process?

Judicial rulings in this area reveal that a two-stage process for resolving conflicts in the paediatric setting is usually recommended: first, the parties in dispute should strive for consensus; and, second, if consensus ultimately cannot be reached, the matter should be referred to the court for a decision. Unfortunately, each of these stages present problems. The consensus-building stage can be captured by the phrase 'shared decision-making'. Successive rulings have emphasised the need for a partnership-based approach, such that the 'choice of treatment is in some measure a joint decision of the doctors and the court or parents'.³⁰ This idea commands some support in relation to adult patients, especially given its autonomy-respecting orientation.³¹ However, it is open to question whether the idea translates easily to proxy decision-makers and thus to exercises of *parental* autonomy.³² This translation must rest on the assumption that parents have *authority*, i.e. a right of say, over the lives of their offspring. Such authority might appear self-evident, but doubts about its basis arise,³³ for example, when the courts indicate that even estranged or incapacitated parents will retain some right of say.³⁴

If, however, we ignore these doubts and thus recognise a need to respect parental authority, the next question is whether such authority is *actually* respected in (paediatric) practice. Empirical evidence suggests that practice varies.³⁵ As such,

28 G Douglas, *An Introduction to Family Law* (OUP 2004) 173.

29 R Heywood, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' (2012) 20 Med L Rev 29.

30 *Re J* (n 3) 41. See also e.g. *Glass* (n 3); *NHS Trust v B* [2006] EWHC 507; *NHS v A* (n 26); *AB* (n 9).

31 *Ms B v NHS Trust* [2002] EWHC 429 (Fam).

32 Birchley, 'Deciding Together?' (n 6).

33 Birchley, 'You Don't Need Proof When You've Got Instinct!' (n 6); M Freeman, 'Whose Life is it Anyway?' (2001) 9 Med L Rev 259.

34 See for example *An NHS Trust v H* [2013] 1 FLR 1471, [19] (Jackson J).

35 See for example T Moro et al., 'Parent Decision-Making for Life Support for Extremely Premature Infants: From the Prenatal Through End-of-Life Period' (2011) 25 J Perinat Neonatal Nurs 52; HE McHaffie, *Crucial Decisions at the Beginning of Life: Parents' Experiences of Treatment Withdrawal from Infants* (Radcliffe Medical Press 2001).

even in eligible cases,³⁶ we might doubt whether, at least with parents, there is always the ‘true sharing of ethical authority and responsibility’³⁷ once envisaged by the supporters of this ideal.³⁷ Given the tenor of professional guidance (which necessarily follows the legal steer), this is unsurprising: for example, the General Medical Council instructs doctors that working in partnership with parents means that: ‘You must *take account* of their views when identifying options that are clinically appropriate and likely to be in the child’s best interests.’³⁸ On this view, sharing a decision might mean no more than being consulted about the decision.

The scope of parental influence therefore appears to be variable in practice and ill-defined in principle. These problems are then replicated (even accentuated) at the second stage of the process. The courts may say that doctors no longer know best,³⁹ but they still appear inclined to assign weight according not only to the content of the evidence, but also to the identity of the individual providing it. Theis J’s ruling in *AB* exemplifies this, offering a compromise position between the doctors and parents, despite clearly concluding that the infant’s doctors had overlooked crucial evidence. If (albeit only if)⁴⁰ ‘the best interests test ought, logically, to give only one answer’,⁴¹ then surely the doctors’ evidence in *AB* was either right or wrong, and, if it was wrong, it would only be correct to reject it. The courts, however, are not quite willing to do this, at least in the majority of such cases.⁴²

These concerns with the process – and particularly with the authority that is accorded to the different parties therein – involve complicated questions of power, and we must always remember the least powerful party: the critically ill infant who is at the heart of the proceedings. Do current processes necessarily serve the infant’s interests, particularly when negotiations are protracted? Lack of clarity on principles and processes may undermine this key aim of the law. In both *AB* and *Reyhan*, many months were devoted to finding a solution to apparently intractable dilemmas, yet it is unclear at what point attempts to reach agreement should be judged to have failed and the courts approached. In *AB*, continued communication had not yielded consensus, despite the relatively narrow basis of the disagreement (both parties, after all, favoured withdrawal), and this was so notwithstanding some apparently correctable misunderstandings (the parents’ wishes were based on observations of their infant of which doctors were unaware). If, as in these cases, disagreement between parents and clinicians eventually leads to court action, then we might expect this to happen promptly

36 Assuming we can specify those cases.

37 R Veatch, ‘Models for Ethical Medicine in a Revolutionary Age’ (1972) 2 Hastings Center Report 5, 7.

38 General Medical Council, Treatment and Care Towards the End of Life: Good Practice in Decision Making (GMC 2010) 46, emphasis added; cf. Nuffield Council (n 1) 22.

39 See Brazier (n 11) 415.

40 See Parker (n 22); Huxtable (n 21).

41 *Re S (adult patient: sterilisation)* [2001] Fam 15, 27 (Butler-Sloss P).

42 cf. *Re T* (n 26).

and for the judge to decide without delay.⁴³ However, in *Reyhan*, we have noted the time which Jackson J felt it appropriate to allow, despite having already determined that continued treatment was not in the best interests of the infant.

The costs of courts?

Maybe Jackson J's decision in *Reyhan* shows commendable sensitivity to the parents – but it might also indicate that the courts are not always best placed to resolve the complicated clinical and ethical questions that come before them. The suspicion that the (legally-mandated) processes might not always be working is shared by the participants in BIPIC. Whilst few doubted the courts' capacity to make an authoritative decision, many questioned whether the courts are the ideal environment in which to resolve disputes like the one that arose in *Reyhan*.

Parents certainly viewed the courts' involvement with trepidation, and expressed little confidence in the court having adequate means to reach a satisfactory decision:

Not a judge, no, 'cos they haven't even seen that child. . . . they have no attachment do they?

(P59, parent)

Reservations were also expressed by doctors and nurses. One doctor had grave doubts about engaging with a process which imposed human and financial costs:

It could go to court, it's very stressful, it's expensive, it risks more confrontation between the family and yourself, and we've still got to look after this child, therefore we're not going to, we won't get a judgement not to do this, this is usually a long-term ventilation thing, so we may as well just do it. So we've got children who I feel it's fundamentally wrong that we've ventilated.

(D34, consultant intensivist)

Brazier has also long noted the limitations of the courts in settling conflicts in the clinic,⁴⁴ a critique that she pointedly applies in her commentary on the (prolonged and public) dispute between the parents and doctors of young Charlotte Wyatt.⁴⁵ Two of Brazier's observations are particularly pertinent here. First, by requiring that one party win and another lose, the courts encourage, rather than diffuse, conflict. Whilst a sensitive judge can do much to mediate between combatant parties, this role as a mediator is undermined by his or her status as a judge, since the judge's role is to *decide* – thereby typically signalling that

43 See Children Act 1989, s 1(2).

44 M Brazier, *Medicine, Patients and the Law* (1st edn, Viking Press 1987).

45 *Wyatt* (n 16); Brazier (n 11).

one party is 'right' and the other is 'wrong'. In such a context, principles may be obfuscated rather than openly discussed and misunderstandings incubated by the need of the parties to prepare a case in an adversarial spirit and of the judge to declare a winner and a loser. Second, Brazier notes that law *costs*. In addition to the undoubted emotional costs, recourse to the courts is financially costly.⁴⁶ Brazier has therefore urged consideration of alternative means of dispute resolution, such as no-fault compensation schemes⁴⁷ and mediation.⁴⁸ However, we want to explore a different mechanism, to which Brazier has also referred:⁴⁹ the clinical ethics committee.

From courts to committees?

Because judges have been asked to resolve the case (indeed, clinicians are compelled to consult the courts if consensus is unachievable),⁵⁰ the courts may by necessity depict cases in black-and-white. Of course, the courts are not entirely blind to the multiple ethical shades of grey in which these dilemmas are daubed. In *AB*, Theis J certainly seemed inclined towards accommodating both sides, rather than signalling that there was a 'winner' and a 'loser'.⁵¹ However, we might question whether the compromise imposed in that case appropriately split the difference between the disputing parties. Quite what is an appropriate accommodation requires more transparent ethical assessment than (perhaps) the courts can provide in their role.⁵² If they are wary of peering too closely at such matters, it would appear appropriate to turn the appraisal over to a group that is specifically tasked with such an ethical endeavour.

Whilst not (yet?) formalised in the manner of research ethics committees, the number of CECs are increasing in the UK.⁵³ These multidisciplinary groups, often containing legal and lay members as well as healthcare professionals, usually offer case consultation services that issue advice on individual dilemmas.⁵⁴ Notably many such cases involve the withdrawal or withholding of life-supporting treatment from young or incapacitated patients.⁵⁵ The enterprise has been challenged, not least by those who fear a 'due process wasteland',⁵⁶ but

46 These high costs could deter parties from seeking a legal resolution.

47 Brazier (n 44).

48 Nuffield Council (n 1) 145.

49 Indeed the second author was privileged to share a Manchester stage with Brazier at the second annual UK Clinical Ethics Network (UKCEN) conference in 2002.

50 *Glass* (n 3).

51 *AB* (n 9) [69–70].

52 Huxtable (n 21).

53 UKCEN (n 5).

54 A Slowther, L McClimans and C Price, 'Development of Clinical Ethics Services in the UK: A National Survey' (2012) 38 *JME* 210.

55 UKCEN (n 5).

56 S McLean, 'Clinical Ethics Committees: A Due Process Wasteland?' (2008) 3 *Clinical Ethics* 99.

it also commands some academic support.⁵⁷ But how is the process looked on by those with real experience of these dilemmas in PICU?

Interviews carried out in the BIPIC study revealed insights into both the opportunities for, and the barriers to, recourse to a CEC. Four themes emerged: the participants spoke positively of the possibility of *group decision-making*, but this was seen as reliant on *clinicians' engagement* with the process, and reservations were expressed about *referral* to the committee and the *identity* of its members. First, there was support for involving a group in deciding on these difficult cases, at least from parents and nurses. One parent commented:

it needs to be different for every case really. Almost if there was some kind of team, if there can be a team that looks at every case, . . . and looks at the situation, and looks at the parents, and looks at the lifestyle, and talks with the medical team.

(P62, parent)

Other parents felt that it would be less easy to avoid making a difficult decision if the situation had been scrutinised by a group of people. Some nurses, too, felt that a group decision would relieve the burden on individual parents and doctors, by ensuring that responsibility was shared. Notably, however, these nurses and parents had virtually no practical experience of a CEC, and they commented that the membership and processes of the committee were a mystery. N43, who nursed a patient who was subject to a CEC referral, commented:

I haven't had any personal input from them. I obviously just hear that it's going to the clinical ethics committee and that's as much as you hear really.

(N43, nurse)

Referrals at the interview locations took place only at the instigation of doctors. Notably, these gatekeepers had mixed views about the usefulness of CECs, and engagement with the local committee appeared to depend on location. In Hospital A, for instance, the doctors interviewed (all trainees), were supportive of the involvement of CECs. Reflecting on a referral with which they had been involved, one doctor said:

I'm quite pro the clinical ethics committee. So I thought it was brilliant that the case was brought to be discussed, I thought that was really good.

(D50, trainee intensivist)

Another doctor felt that the advice dispensed was more expert and objective than the decision of a court, which was seen to rely on:

individual judges who have no clinical training – they hear evidence from clinical teams, but these are very much skewed to whichever purpose the

57 Huxtable (n 21).

legal teams want to drive things, and there are inherent interests maintained. Whereas a committee potentially could be more objective because it is a committee decision.

(D47, trainee intensivist)

However, in other study locations, participants were less positive. D30, a consultant intensivist at Hospital B with several decades of experience, was scathing of his local ethics committee, suggesting it was irresolute and inappropriately legally-focused in its advice:

They will give you a set of options, and they will not come back with anything that's of much help at all. Or they will withdraw into the legalistic arguments. It's been very disappointing. And, you know, we've gone to ethics committees several times, more than just me, and we've been highly disappointed with the response . . . you've got too many views going round, and ultimately, if you have so many views, you do nothing. And that's what happens with the clinical ethics committee: they do nothing.

(D30, consultant intensivist)

This type of opinion seemed to depend on the location of the PICU, rather than the seniority of the staff. For example, D27, a trainee intensivist at Hospital B, appeared to view the ethics committee as moribund:

They didn't change the thoughts, they didn't really significantly change the process.

(D27, trainee intensivist)

At Hospital C, there was no engagement with the ethics committee at all. D46, a consultant intensivist, said the committee had no understanding of the types of issues they encountered in PICU, and so it had never been used:

Maybe if you're working in a standalone children's hospital where everyone on the ethics committee understands paediatric issues, it may be more useful. Um, as I say, we don't tend to use our own here so I can't comment on how useful it is or isn't in other places.

(D46, consultant intensivist)

This situation was confirmed by members of Hospital C's clinical ethics committee, who highlighted a lack of referrals. E53, a lay member, felt this was a widespread problem:

I think most other ethics committees, including ours, struggle to get more than a couple of cases a month, and you might not get a case in a month.

(E53, Lay member, clinical ethics committee)

A low level of referrals raised concerns among committee members that cases of real ethical difficulty may be missed. E36, a doctor, observed:

People who bring ethics problems to an ethics committee have realised there is an ethical problem. . . . I think the areas where potentially unethical practice goes on is when it hasn't crossed anybody's mind that there is an ethical issue whatsoever.

(E36, Doctor, clinical ethics committee)

At the same time, however, some committee members were wary of expanding the referral base by accepting referrals from non-clinicians. Whilst some parents expressed enthusiasm for committee advice, only one parent felt that they would have benefitted personally from this. However, although some ethics committee members were supportive of accepting referrals from patients or families, others were guarded:

I think in certain cases it might be useful. I don't think in all cases, because often the reason that there is a referral [to the committee] is there is some sort of chaotic family life or there's some [other] reason why.

(E53, Lay member, clinical ethics committee)

Other members felt that referral was proscribed, given the committee's occupancy of the hospital institution:

with parents one has to bear in mind that they may end up in litigation against our employer institution, um and what we say might be used against us.

(E39, lawyer, clinical ethics committee)

E39's concern introduces a new problem: the committee's ability to command the respect of the disputants. For clinicians, a recurring concern was the authoritativeness of the committee's opinion:

I don't know that there is great buy-in to what it says, is the problem. You know, if they come up with a kind of opinion, and you've still got two groups that one group is not going to agree with the opinion.

(D34, consultant intensivist)

Parents considered expertise to be an essential element in engendering the confidence of all the parties:

As long as you felt confident, . . . that they had enough expertise in the areas that they were going to sort of discuss, and by expertise I mean, you know, they understood some of the repercussions medically, then

yeah I don't think that's a bad thing if things are becoming sort of at an impasse.

(P45, parent)

Whilst ethical and medical expertise would thus help to command the respect of parents and professionals alike, the issue of authoritativeness remained a vexed issue for many clinicians.

Analysis of the results from BIPIC gives us some cause for reflection upon the (current and future) role that a CEC might play in disputes over a child's best interests. Although some participants welcomed the involvement of ethics committees, the BIPIC study revealed variation in the perceived effectiveness of these groups, challenges in access, and questions about their identity and authority. If there is merit in providing such a service, then efforts will be needed to address these concerns. Variations in user perceptions mirror real variations in committee membership and procedure.⁵⁸ If some committees command the respect of clinicians, and some do not, then we must learn from those committees that are judged to be operating 'successfully'.

This could follow the model of identifying good practice that can be replicated elsewhere, or more radically, could point to a need for a national committee framework, with specially-convened sub-committees with subject-specific expertise. A low level of referrals could also signal a need to open up the referral system, so that (as indeed Brazier has suggested) we can hear the voices of those who might otherwise be missed – including not only the parents but also the nurses.⁵⁹ If power needs to be rebalanced, then there may even be a need to revisit the composition of committees, with a view to ensuring that there is appropriate medical expertise, but that this does not wholly dominate deliberations. Indeed, composition, training and the very notion of 'expertise' are likely to be particularly pressing concerns.

Of course, all of these proposals also raise questions. Organisationally, the current system is *ad hoc* and run on a voluntary basis, often by time-pressed chairpersons. Could the present structure cope with increased levels of referral? How is due process to be assured?⁶⁰ Should the system be formalised, along the lines of the research ethics committee? Issues of governance also need attention: non-medical referrals may challenge traditional hierarchies, and parental referrals need to be channelled in a way that differentiates the ethics consultation from the patient advice and liaison service. Finally, the vexed question of expertise will remain: judges may be self-evident experts in law, but what does an ethical expert look like?⁶¹ Whilst we cannot resolve these questions here, we suspect

58 Slowther et al. (n 54).

59 Brazier (n 11) 416.

60 McLean (n 56).

61 Huxtable (n 21).

there ought to be an active search for answers, especially if there is a case for improving on the current processes, whilst also engaging effectively with what are not only legal, but also ethical principles.

Conclusion

In cases involving critically ill infants, as Brazier notes, it may be that '[t]here is no right answer'.⁶² There may, however, be processes available that can engage appropriately with the principles (plural) and thus ensure that all of the relevant rights and wrongs are aired, in a timely fashion. Like Brazier, the BIPIC participants noted the costs imposed by recourse to the courts, not least because the adversarial process can exacerbate, rather than ameliorate, the dispute. Rightly or wrongly, the legal process – and even the prior process of consensus-building – would appear to be weighted against parents. Whether this is indeed right or wrong should be established: if, despite the ethically-laden nature of the best interests mantra, the courts are reluctant to peer too closely at these matters,⁶³ then we need a forum in which the exploration can occur.

CECs appear to offer the obvious location. From this point of view, the BIPIC results contain both positive and negative messages. CECs may be both desirable and appreciated, at least in some quarters. But, on a local level, relations between clinicians and committees apparently vary from good to non-existent, committees remain under-utilised and doubts remain over their authority and expertise. These challenges need to be overcome if the current service is to develop. Ideally, for parties to future cases akin to *Reyhan* and *AB*, we should be able to devise a system that combines the best of both worlds, i.e. the decisive authority of the courts coupled with the sensitive ethical reflection of an appropriately composed and constituted ethics committee.

62 Brazier (n 11) 418.

63 Montgomery (n 4).